

## What Is a Seizure?

A seizure is an abnormal release of electrical activity in the brain that causes temporary changes in how a person moves, feels, or thinks.

- Seizures can take many different forms, including whole-body convulsions/shaking or changes in awareness or behavior.
- Where the seizure occurs in the brain determines what the seizure looks like.
- Seizures can last from a few seconds to several minutes.
- One in 10 people will have a seizure in their lifetime.

Seizures are classified as either focal or generalized onset. Focal seizures begin in one area in the brain, while generalized seizures affect multiple areas or the entire brain.

Depending on which areas of the brain are involved, seizures may cause a variety of symptoms, including altered awareness, uncontrolled physical movements, sensory impairment, intense emotional reactions, convulsions, and loss of consciousness. It is possible for someone to have more than one type of seizure.

## What is Epilepsy?

Epilepsy is a neurological (brain) condition that causes people to have recurring seizures, and is typically diagnosed after two or more unprovoked seizures. Epilepsy is sometimes referred to as a seizure disorder.

- Epilepsy is not contagious.
- Epilepsy is a medical condition, like diabetes or asthma.
- Epilepsy is not a mental illness or impairment.
- Epilepsy is the fourth most common neurological condition, after migraines, stroke, and Alzheimer's disease.

In the United States, 3.4 million people live with epilepsy, including nearly half a million children. It's most often diagnosed in childhood or after the age of 65, but can occur at any age. It affects people of all races, genders, religions, ethnic backgrounds, and social classes. One in 26 people will develop epilepsy in their lifetime.

## How to Respond to Seizures?

It's important that those around you know how to respond if you have a seizure. Whatever the seizure type, there are general guidelines to remember:

- Time the seizure if possible.
- Keep the person safe from injury.
- Don't put anything in the mouth (except rescue medications, if prescribed).
- Never hold down or restrain a person having a seizure.
- If their awareness is impaired gently direct them away from any hazards.
- If they are convulsing, turn them on their side if possible, cushion their head with something soft, and remove glasses and loosen tight clothing.
- Stay with them until the seizure ends, then offer reassurance and comfort.
- Most seizures are not medical emergencies.
- Call 911 for a seizure lasting more than 5 minutes. Most seizures last less than 2 minutes.

## Causes of Epilepsy

Epilepsy can be caused by a variety of conditions that affect the brain; however, for about 70% of people with epilepsy the cause is unknown. Some of the known causes include:

- Stroke.
- Brain tumor.
- Head trauma and/or brain injury.
- Brain infections.
- Neurological diseases such as Alzheimer's.
- Brain malformations.
- Lack of oxygen during birth.
- Genetic factors.



## Levels of Care in Epilepsy

One of the first steps after being diagnosed with epilepsy is to assess the level of care needed. The type of doctor you see first may depend on the severity of your symptoms and your individual circumstances. There are several options for care in epilepsy:

- Your **primary care provider (PCP)** may be the first level of care if you suspect something is wrong. Your PCP can check to make sure your symptoms aren't caused by other conditions that mimic seizures. Some people whose seizures are easily controlled with medication may continue to have their epilepsy managed by their PCP.
- A **neurologist** is a doctor who specializes in treating diseases and disorders of the brain and central nervous system, including epilepsy. Most individuals with epilepsy receive their care at this level.
- An **epileptologist** is a neurologist with an additional 1-2 years of specialized training or certification in treating epilepsy. If your seizures are proving difficult to control with medication, you may want to seek out an epileptologist.
- A **comprehensive epilepsy center** is a specialty clinic for the treatment of epilepsy and related conditions. It provides a comprehensive approach to treatment, and will often have epileptologists, psychologists, neuropsychologists, neurosurgeons, social workers, and other staff who work as a team. Centers offer advanced testing and treatment options that may not be available at a general neurology clinic. A comprehensive epilepsy center is recommended for those who are continuing to have seizures after more than a year of treatment, have tried and failed two or more medications, are experiencing unacceptable side effects, or have co-existing conditions like autism, mental health concerns, or pregnancy.

## Talking to Your Doctor

Getting good medical care for epilepsy means working as a team with your doctor. Seizures rarely happen during appointments, so your doctor relies on you to share the information needed for proper diagnosis and care. Some things they'll need to know, beginning with your first visit and moving through treatment:

- Your medical history — this can help determine if a past injury or illness could have caused damage to the brain leading to seizures.
- Whether you are being treated for other conditions, as it could affect the medications your doctor prescribes. Make a list of all medications you take and any allergies.
- As much detail as possible about the seizure or event, including any contributing risk factors such as a new medication, fever, sleep deprivation, alcohol, or drug use. Because you may be unaware of what happened, eyewitness accounts or even a video are helpful.
- Track and record the frequency, time of day, and what happens before, during, and after seizures. Keep a seizure diary and look for patterns that might indicate seizure triggers. Bring the seizure diary with you to your office visits. This may help your doctor make a diagnosis and guide their treatment recommendations.
- Any side effects or other health problems you're experiencing.
- How epilepsy is affecting you and your family.



## It's important to prepare for appointments to make sure you get the most out of your doctor visits:

- Write down any questions or concerns you want to discuss. Put the two or three most important questions at the top of the list so you're sure to have time to ask.
- If time runs out, ask to make another appointment to address your remaining questions.
- Don't be afraid to share concerns about depression, anxiety, or other mental health issues. These things are just as important as seizure control in living well with epilepsy.
- Make sure you understand your doctor's recommendations. If they use language you don't understand, stop and ask them to explain. You need to understand and follow your treatment plan for it to work.
- Be honest with your doctor if you don't always take your medicine, if you can't afford your prescriptions, if you are having side effects or don't feel well, or if you are still having seizures (even small ones). Your doctor can only help you if they have all the relevant information.
- Ask what to do if you have questions after you get home. Find out who you can call and when.



## Medication is usually the first treatment option for epilepsy. Here are some questions to ask when starting a new medication:

- What do I do if I forget to take my medication?
- What side effects does it have? What should I watch out for?
- Why did you choose this medication? Are there other ones that I could take?
- How often will I need blood drawn or other tests done?
- Is it OK for the pharmacist to give me a generic version of this medication, or should I have the brand-name version?
- Are there any foods, drinks, or activities that I should stay away from while I'm taking this medication?

## Things your doctor considers when trying seizure medication include:

- Seizure type.
- Medication side effects.
- Other medications you may be taking.
- Person's age (avoid sedating medicines or one that affect thinking or moving in an older person).
- Effect on having children in women of childbearing age.
- Effect of medication on bone health, mood, and other health concerns.

**A new diagnosis of epilepsy can feel overwhelming, but working in partnership with your doctor can help you feel more confident as you work toward seizure control.**

Managing your epilepsy, also called self-management, includes everything you, your family, and support network do to control seizures, manage epilepsy's effects on your daily life, and live life to your fullest potential. It doesn't mean you manage epilepsy by yourself. **It does mean** you work together with your healthcare team, family, and other supports.

## Medications

The majority of people with epilepsy, about 70%, are able to control their seizures through medication. There are over 30 different anti-seizure medications on the market today, and your doctor will prescribe one or more based on your seizure type and medical history. You may need to try more than one medication before finding what works for you.

Give your treatment plan the best chance of success:

- Take your medication regularly as directed by your doctor.
- Ask your doctor or pharmacist about possible side effects.
- Do not skip doses or change the dose without consulting your doctor. Too much medication can cause side effects, and too little can increase seizures.
- Do not stop taking your medication suddenly. This can lead to a dramatic increase in seizures and be very dangerous.
- Ask your doctor if it's safe to drink alcohol, and in what amounts.
- When starting a new medication or making a major change in dosage, use caution and don't drive until you know how it affects you.
- Write down the name, strength, and dosage of your medication so you can refer to it as needed.
- Inform all of your doctors, dentists, and pharmacists that you are taking anti-seizure medication.

All anti-seizure medications come with possible side effects, but they may not occur for every individual. Some of the more common side effects are drowsiness, fatigue, lethargy, headache, difficulty concentrating, irritability, changes in appetite, and mood changes. Some side effects are potentially serious, including severe rash, liver toxicity, or suicidal thoughts. Ask your doctor about the potential side effects of the medicine they prescribed, and always report any worrisome side effects to them right away.

Some side effects may be temporary, and will go away as your body adjusts to the medication. In other cases, changing the dosage or schedule may reduce or eliminate the side effects. If you experience unpleasant side effects from your medication, work with your doctor to find a solution. This may mean switching to a different medication.

Your doctor may prescribe a rescue, or emergency, medication. These are used in emergency situations to stop a seizure that will not stop on its own. There are various emergency medications available that can be administered in rectal, buccal (between the cheek and the gum), sublingual (under the tongue), or nasal form.



## Seizure Triggers

Some people find that certain situations, habits, health problems, or medications affect their seizures. These are known as seizure triggers. Some examples of seizure triggers include:

- Missing seizure medication doses or stopping them suddenly.
- Not getting enough sleep or low quality sleep.
- Stress.
- Being sick with another illness or fever.
- Flashing lights in people who are photosensitive.
- Menstrual cycles or other hormonal changes.
- Alcohol or drug use, including the day after drinking.
- Certain prescription or over-the-counter medications.
- Some herbal products or supplements.
- Low levels of certain minerals or substances in the body (for example, sodium, magnesium or calcium).

Focus on your overall health and create healthy daily routines to help avoid triggers and improve seizure control. Here are some ideas:

- Keep a regular sleep pattern. Go to bed and get up at the same time each day.
- Drink plenty of fluids and stay hydrated.
- Pay attention to your overall emotional health.
- Eat regularly and have a healthy diet.
- Have a strong support system of family and friends.
- Exercise in a safe manner. Avoid getting overheated, overtired, or dehydrated.
- Learn strategies to reduce and respond to stress.
- Keep a seizure diary to track your progress.

Seizures can pose additional safety concerns depending on when and where they happen. Look at your environment at home, work, or school, as well as the activities you participate in, to identify hazards and potential safeguards.

## Water Safety:

- There is serious risk of drowning if a seizure occurs in a bath or hot tub. Take showers instead, and consider using a shower chair to minimize falls.
- Hang the bathroom door so it swings out, not in, so it can't be blocked from opening in case of an emergency.
- Don't lock the bathroom door; instead hang a sign to indicate it's in use.

## Fire Safety:

- Sit far back from open flames, such as a campfire.
- Electric stoves may be safer than gas (due to flames). Using a microwave or an induction range is even better.
- Cook on the back burner. You are less likely to lean on the burner or spill hot foods on yourself or others during a seizure.
- Set the maximum hot water temperature in your house to 110 degrees Fahrenheit.
- Put guards on open fireplaces, wood stoves, or radiators.
- Don't smoke or use matches when you're alone.

## Safety from Falls:

- Pad sharp corners on furniture.
- Install thick carpeting and avoid throw rugs.
- Avoid glass tables that could shatter in a fall.



## Sleep Safety:

- Sleep in a bed that is low to the floor if you have seizures at night.
- Consider using a seizure alert device so someone knows when you have a seizure and can check on you.
- If you have shaking movements during a seizure, move your bed away from furniture or the wall.
- Sleep on your back or side. Don't sleep face down.

## Driving

The ability to drive, and the independence it allows, is a major concern for people with epilepsy. In Minnesota, people with epilepsy can legally and safely drive under certain guidelines:

- You must be seizure-free for three months to get a license or permit, or to have driving privileges reinstated following a seizure.
- If you have a driver's license, you must report a seizure to the state within 30 days. At that time, your license will be cancelled until you report that you have been seizure-free for three months.
- Your doctor must certify that you are cleared to drive before your license is reinstated.
- Follow-up reporting is required at six months, one year, and then every four years.
- The required reporting form is available on the Department of Public Safety's website or from EFMN.
- Exceptions to license cancellation may be made if the seizure was due to temporary illness, occurred under a physician's order to change or withdraw medication, or was the first seizure experienced by the driver within four years.
- Doctors in Minnesota are not required to report a patient's seizures to the state, but may do so if they believe the person will not report and is continuing to drive.

Epilepsy is the 4th most common neurological disease and has been diagnosed in 65 million people worldwide. Like cancer, epilepsy is not a single disease. It comprises many different causes, which are grouped into five categories:

- Genetic — Passed down through relatives or caused by a gene mutation.
- Structural — Physical difference in the brain.
- Metabolic — Caused by chemical reactions in the body.
- Immune-related — Changes in the body's immune system.
- Infection — Previous infection causing recurring seizures.

Although epilepsy as a diagnosis is not rare, specific types of epilepsy are. When the underlying cause of epilepsy impacts fewer than 200,000 people, it's considered a rare epilepsy.

## Diagnosis

Knowing the specific cause of your epilepsy can help your healthcare team make better decisions regarding treatment. Unfortunately, 50% of all people diagnosed with epilepsy do not know the cause. If you or a loved one is among that 50%, what can you do?

- Advocate to your doctor for the chance to learn the cause of your epilepsy.
- Ask if you or your loved one are good candidates for genetic testing.
- Request a referral to a comprehensive epilepsy center where the most advanced diagnostic testing is available. get up at the same time each day.

There are more than 40 different seizure types, and individuals with rare epilepsies often have more than one. Their seizures may also be refractory or intractable, meaning they do not respond to anti-seizure medications.

## Comorbidities

Comorbidities are when an additional medical disorder is present alongside an epilepsy diagnosis. There are many comorbidities associated with rare epilepsies, including:

- Cognitive issues like memory or learning disabilities, language disorders, and developmental delays.
- Psychiatric concerns like anxiety, depression, and Autism Spectrum Disorder.
  - Behavioral concerns.
- Medical issues like mobility, sleep, respiratory system disorders, gastrointestinal and digestive disorders, and migraines.

## Treatment

When rare epilepsies don't respond to standard treatment with anti-seizure medications, other options include surgery, devices, or dietary therapies. Researchers are working to develop precision therapies using individuals' genetic information to develop a customized treatment plan using gene therapy and other new technologies.

## Resources

The Rare Epilepsy Network is working to further research into rare epilepsies to ensure a better future for those living with these conditions. They operate a Rare Epilepsy Registry to help advance that research. Their website, [rareepilepsynetwork.org](http://rareepilepsynetwork.org), also has links to dozens of organizations representing individual rare epilepsies.



## Diagnosis

While epilepsy can develop at any stage of life, when the first seizure occurs in the adult years there are special considerations:

- Focal seizures are more common than generalized seizures in adults. Because focal seizures are sometimes overlooked or mistaken for something else, it's important to track what you are experiencing by keeping a seizure diary. If possible, have someone record your seizures on video or through a written description of what happens.
- Delays in diagnosis can make it harder to get your seizures under control and affect your quality of life.

## Causes of Epilepsy in Adults

In young and middle-aged adults, common causes of epilepsy include:

- Head injuries.
- Brain infections.
- Brain tumors.

In adults over age 55, common causes include:

- Stroke.
- Alzheimer's or other degenerative diseases.
- Infections.
- Tumors.

When a cause can't be determined, genetic factors may play a role.

Knowing the specific cause of your epilepsy can help your healthcare team make better decisions regarding treatment. Unfortunately, 50% of all people diagnosed with epilepsy do not know the cause. If you or a loved one is among that 50%, what can you do?

- Advocate to your doctor for the chance to learn the cause of your epilepsy.
- Ask if you or your loved one are good candidates for genetic testing.
- Request a referral to a comprehensive epilepsy center where the most advanced diagnostic testing is available.

## Related Conditions

Conditions that occur alongside epilepsy are called comorbidities. Common comorbidities in adults with epilepsy include:

- Depression.
- Other mood disorders, including anxiety and bipolar disorder.
- Attention Deficit Hyperactivity Disorder (ADHD).
- Learning problems that interfere with employment and education.
- Physical problems that can cause unusual tiredness, headaches, etc.
- Social issues that make friendships and activities difficult.

## Employment

People with epilepsy are able to work in many different types of jobs, including some safety-sensitive jobs like law enforcement. There are usually only a few jobs, like flying airplanes, that people with epilepsy cannot do and/or jobs that have regulatory limitations such as commercial truck driver.

Your employer cannot discriminate against you because of your epilepsy thanks to the protections of the Americans With Disabilities Act (ADA). You do not have to tell your employer you have epilepsy. However, there are reasons you may want to, such as, if you need reasonable accommodations (changes), or think you may have a seizure at work.



## Pregnancy and Childbirth

Most women with epilepsy can have healthy pregnancies and deliveries, but you'll need to take extra steps to stay healthy, control seizures, and keep your baby safe.

- Before getting pregnant, talk to your healthcare team about whether your anti-seizure medication is safe to use during pregnancy.
- While pregnant, get blood tests to make sure you're getting the right amount of medication since pregnancy can change how your body absorbs seizure medication.
- Talk to your provider about how you can safely breastfeed.



---

### Take Action:

Identify the people you are comfortable sharing your epilepsy diagnosis with.

---

## Telling Friends and Family

You may be nervous telling people about your epilepsy. Keep in mind that you don't have to tell everyone right away. When you're ready, here are tips to help:

- Remember that your true friends want to support you.
- Your friends may have wrong ideas about what it means to have epilepsy. Explain that it's simply a medical condition, and it doesn't change who you are.
- Make sure friends and close family know how to respond if you have a seizure. We can help with information about seizure recognition and response.
- Fill out the included Seizure Action Plan, sharing copies with those close to you.

If you have children, explain your epilepsy to them in simple terms they can understand.

- Make sure they know it's a medical condition, like asthma or diabetes.
- Encourage them to ask questions about epilepsy.
- Reassure your children that seizures are not usually dangerous even though they may look scary.
- Talk to them at their level of understanding, with age-appropriate information.
- Make a plan for what to do if you have a seizure when they are with you. For example, they might call a speed dial number or provide initial protection and first aid.

Epilepsy affects children at different ages and in different ways. For some, it's a temporary problem, easily controlled with medication and possibly even outgrown after a few years. For others, it's a lifelong challenge affecting many areas of life.

Epilepsy in children:

- May be associated with serious, difficult-to-treat syndromes, including Lennox-Gastaut syndrome, genetically related conditions, and developmental disorders.
- Social impact in childhood can produce feelings of isolation and loss of self-esteem.
- Early recognition and treatment are keys to the best possible outcome.
- Potential educational and learning difficulties due to epilepsy or medication side effects.

Common causes of childhood epilepsy:

- Genetic causes.
- Head injury.
- Infections of the brain and its coverings.
- Lack of oxygen or circulation to the brain during pregnancy or deliver.
- Disorders of brain development.

Knowing the specific cause of your child's epilepsy can help healthcare providers make better decisions regarding treatment. Unfortunately, 50% of all people diagnosed with epilepsy still do not know the cause. If your child is among that 50%, what can you do?

- Advocate to their doctor for the chance to learn the cause of the epilepsy.
- Ask if they are a good candidate for genetic testing.
- Request a referral to a comprehensive epilepsy center where the most advanced diagnostic testing is available.

## Related Conditions

Conditions that occur alongside epilepsy are called comorbidities. Common comorbidities in children with epilepsy include:

- Depression - estimated to affect at least 25% of children with epilepsy.
- Other mood disorders, including anxiety and bipolar disorders.
- Attention Deficit Hyperactivity Disorder — 40% of children with epilepsy are diagnosed with ADD/ADHD.
- Learning problems that interfere with schoolwork.
- Physical problems that can make them unusually tired or cause stomach pain, headaches, etc.
- Social issues that make friendships and activities difficult.

## Talking to Your Child About Epilepsy

Your child needs help understanding their epilepsy. Tell them what they need to know, but don't overwhelm them.

- Make sure your child understands that epilepsy is a medical condition, like asthma or diabetes.
- Let your child ask questions and talk about their fears.
- Remember that conversations can happen over time and you don't need to cover everything at once.
- Help your child learn to talk about epilepsy as a part of life and not as something to hide.
- Have a conversation about what certain people may need to know and why (like teachers or the school nurse).
- Let your child know they don't have to share more information with friends than they want to.

## School and Friends

Having seizures at school can be hard for your child and scary for their classmates, but it doesn't have to be. Talk with your child's teacher, the school nurse, and school administrators about what they can do to support your child. Our staff can help with this.

- Make sure your child can take medication at school. Most schools won't let kids give themselves medication, but you can arrange for an adult to do so.
- Talk to your child's teacher and school officials about how epilepsy affects your child, what happens when they have a seizure, and what the teacher needs to do in case of a seizure.
- Fill out the included Seizure Action Plan and give copies to their teacher and school.
- Watch out for signs of bullying and talk to your child's teacher or principal if you believe it's happening.
- Be alert for signs of learning challenges. As a parent, you have the right to request an assessment of your child's learning challenges and needs. You should ask whether an Individualized Education Plan (IEP) is right for your child.



---

## Take Action:

**Check in with your child today and give them an opportunity to share feelings or ask questions related to their epilepsy or seizures.**

---

The Epilepsy Foundation of Minnesota (EFMN) supports people impacted by epilepsy. This includes youth and adults with epilepsy, as well as parents, caregivers, and siblings. No one journeys through epilepsy alone, and our programs and services make it easy for you to create a support system with others who understand the journey you're on.

## Newly Diagnosed Support

Making sure individuals and caregivers get the information and support needed following an epilepsy diagnosis. For the first 90 days, we follow up with you every two weeks via your preferred method of communication. This is to offer personalized support and check in on progress, address new challenges, and answer any questions you have. After the first 90 days, there's an additional follow up at six months.

## Information Services

From diagnosis through treatment, our Information Services staff offer free, one-to-one support for all people impacted by epilepsy. Contact us to talk through whatever challenges you face or questions you have, such as medication side effects, driving, employment, education support for students, and more.

## Connect Groups

A space to meet others on a similar epilepsy journey. Connect Groups are available to youth, teens, adults, and parents/caregivers. They're designed for people to offer peer-to-peer support, share experiences, and ask questions.



## Youth Programs

Growing up with epilepsy brings unique challenges and our youth-specific programs include summer camps and the Shining Stars program. Both are specific to youth and teens under 18 years of age, and offer fun environments for families impacted by epilepsy to find community and meet others.

## Seizure Recognition & Response Training

Safety is a high priority and thus schools, workplaces, and community groups should know how to recognize and respond to someone having a seizure. Trainings can be requested for groups and organizations that are part of your life.

## Personal Education

Webinars and trainings focused on educating and empowering individuals with epilepsy and their caregivers. Designed to make sure you have the knowledge and confidence to lead a healthy lifestyle.

---

## Take Action:

Schedule a one-to-one meeting with the staff who gave you this toolkit, or write down questions to ask during our next check-in call.

---

## Seizure Timers and Trackers

Tracking seizures is a crucial part of seizure management. Everyone with epilepsy should find a seizure tracking method that works for them, from using an app to tracking in a paper diary. This information is useful when talking with your doctor and measuring progress over time. Options include but are not limited to:

### Nile

[nile.ai/app](https://nile.ai/app)

- Online seizure diary with a companion smartphone app.
- Manage medications, track side effects, and use of rescue therapies.
- Easy-to-use reminders to prevent missed medications or appointments.
- Share your seizure with a family member, caregiver, or clinician.
- Track triggers and lifestyle to lessen risk of breakthrough seizures.
- Communicate more easily with your healthcare team.
- FREE.

### Seizure Tracker

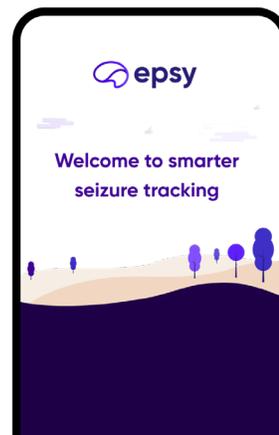
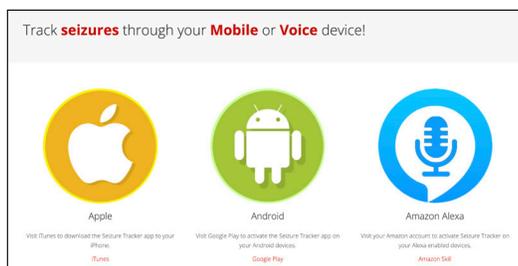
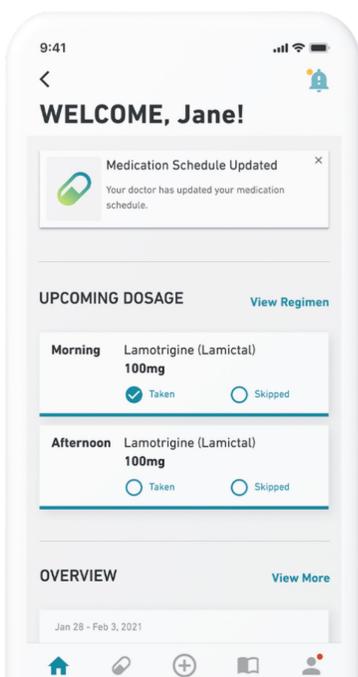
[seizuretracker.com](https://seizuretracker.com)

- Track seizures, appointments and medication schedules.
- Downloadable seizure logs.
- Graphs comparing seizure activity and medication dosages.
- FREE.

### Epsy

[eppsyhealth.com](https://eppsyhealth.com)

- Online seizure diary with a companion smartphone app.
- Manage medications, track side effects, and use of rescue therapies.
- Easy-to-use reminders to prevent missed medications or appointments.
- Share your seizure with a family member, caregiver, or clinician.
- Track triggers and lifestyle to lessen risk of breakthrough seizures.
- Communicate more easily with your healthcare team.
- FREE.



## Medication Reminders

Successful self-management of epilepsy requires taking medication as prescribed. It's not always easy, especially when seizures or medication cause memory problems. Consider using an app like those listed below to help you stay on schedule.

### Medisafe

[medisafeapp.com](https://medisafeapp.com)

- Provides personalized reminders to take your medications.
- List caregivers or friends as a “Medfriend” to send them a notification if you accidentally miss a dose.
- Manage your family members’ medications from one convenient place with the dependents feature.
- Get an alert for drug interaction warnings.
- Refill reminders when you’re running low on medication.
- Premium app with additional features available for a monthly or annual fee.
- FREE.

### MyTherapy Medication Reminder

[mytherapyapp.com](https://mytherapyapp.com)

- Combines a pill tracker, mood tracker, and health journal.
- Receive reminders for all your medications.
- Pill tracker with a logbook for both your skipped and confirmed intakes.
- Refill reminders when you’re running low.
- FREE.

### Pill Reminder - All in One app

[Search on the Apple app store](#)

- Track seizures, appointments and medication schedules.
- Downloadable seizure logs.
- Graphs comparing seizure activity and medication dosages.
- FREE.

### TabTime Time

[Search on amazon.com](#)

- Not an app, but a physical timer that can be set for up to eight different alarms.
- Good for those without smartphones who need an audible reminder.
- One inch high and just over 3 inches in diameter. Fits easily into a pocket, purse, or backpack.
- Costs between \$15 and \$25.

---

## Take Action:

**Try one of the listed seizure tracking options and decide if it's the right one for you.**

---

## Mental Health

Epilepsy is not a mental illness, but it often coexists with psychiatric and other neurological disorders. In fact, 25-50% of individuals with epilepsy will be diagnosed with a psychiatric disorder. The most common in adults with epilepsy are mood and anxiety disorders, and the most common among children are Attention Deficit Hyperactivity Disorder (ADHD), anxiety, and depression.

Sometimes, a change in anti-seizure medication can alleviate mental health symptoms. For others, the addition of an antidepressant or anti-anxiety medication, and/or mental health counseling may be beneficial. Resources include:

- [People Incorporated](#) has an epilepsy program that helps individuals receive services to support their independence, including connecting them with mental health professionals.
- Most comprehensive epilepsy centers have psychologists on staff who work with patients experiencing psychological problems.
- [The National Alliance on Mental Illness of Minnesota \(NAMI MN\)](#), works with individuals with mental illness, their families, professionals, and the community at large by providing education, support, and advocacy.

## Stress Management

Even if you don't have a diagnosed mental health disorder, epilepsy can still negatively impact emotional health. While stress can be a trigger for seizures, living with epilepsy and the unpredictability of seizures can also cause stress, resulting in a continuous cycle that's hard to break.

Strategies like meditation, deep breathing, adequate sleep, exercise, and good nutrition can all help in reducing stress. If you need guidance in de-stressing, apps like [Calm](#) and [Headspace](#) can help. Both are paid services, but offer free trial downloads. You can also find free options on YouTube by searching "free guided meditation."

## Social Connection

Living with epilepsy can feel lonely and isolating. Seeking out support and connection from others on their own epilepsy journey can help reduce these feelings and enhance wellbeing.

- [EFMN Connect Groups](#) – Connect Groups help you meet others on a similar journey and share experiences in a safe and supportive environment.
- [My Epilepsy Team](#) — An online social network where you build a support team based on the criteria you choose. That could mean people living near you, those who share similar symptoms or treatments, people with shared interests and hobbies, or anyone you feel a connection to.



## Take Action:

Visit our online calendar and see the upcoming events designed to help you meet others.

Sudden Unexpected Death in Epilepsy (SUDEP) is when an otherwise healthy person with epilepsy dies unexpectedly and no cause of death is found. While rare, each year about 1 in 1,000 adults and 1 in 4,500 children with epilepsy die from SUDEP. This is the leading cause of death in people with uncontrolled seizures.

No one is sure about the cause of death in SUDEP. Some researchers think that a seizure causes an irregular heart rhythm. More recent studies suggest that the person may suffocate from impaired breathing, fluid in the lungs, or being face down.

SUDEP can happen at any time and with any type of seizure. It happens most often in people with:

- Tonic clonic seizures.
- Uncontrolled seizures.
- Seizures at night.

Keeping your seizures controlled is the best way to reduce the risk of SUDEP.

- Take medications as scheduled.
- Know your seizure triggers and avoid them.
- Avoid excess alcohol and use of recreational drugs.
- Live a healthy lifestyle, with adequate sleep, good nutrition, and regular exercise.

SUDEP is a difficult subject to talk about, and some doctors are reluctant to bring it up. But getting educated is the first step toward finding ways to minimize the threat.



---

## Take Action:

During your next appointment, ask your doctors about your SUDEP risk and ways to reduce it.

---